DOCUMENT RESUME

ED 327 017 EC 232 664

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TITLE Invest in Virginia's Future...Prevent Developmental Disabilities.
INSTITUTION Action for Prevention, Inc., Richmond, VA.; Virginia Commonwealth Univ., Richmond. Virginia Inst. for Developmental Disabilities.
SPONS AGENCY Virginia State Dept. of Mental Health and Mental Retardation, Richmond. Developmental Disabilities Unit.
PUB DATE Dec 89
CONTRACT VA-MH-MR-89-07
NOTE 25p.; For a related document, see EC 232 663. Photographs will not reproduce well.
PUB TYPE Reports - Descriptive (141) -- Viewpoints (120)

EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS *Accessibility (for Disabled); Citizen Role; Community Role; Delivery Systems; *Developmental Disabilities; Elementary Secondary Education; Environmental Influences; Evaluation Needs; Genetics; *Health Services; *Injuries; Perinatal Influences; Preschool Education; *Prevention; Public Policy; Public Service; Research Needs; *Social Action; State Standards
IDENTIFIERS *Virginia

ABSTRACT

This document presents the priorities of Action for Prevention, Inc. for the prevention of developmental disabilities in Virginia in the 1990's. The priorities were selected from recommendations developed by four task forces on genetics, perinatal, early childhood, and school age/adolescence. The document is intended to contain recommendations that are doable, manageable, and of significance for a variety of audiences in promoting the prevention of mental retardation/developmental disabilities. Recommendations are grouped into four areas: education and citizen awareness, access to quality care, environmental hazards and injuries, and research and evaluation. For each area, a description of the general problem is offered along with specific facts (usually containing statistical data) and recommendations. Participants in developing the recommendations are listed. (JDD)

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December 1989

.....PREVENT DEVELOPMENTAL DISABILITIES

AN ACTION AGENDA FOR THE 1990's

INTRODUCTION

Action for Prevention, Inc., a voluntary non-profit organization, was established to promote the prevention of mental retardation and other developmental disabilities in Virginia. Membership in Action for Prevention, Inc. includes public and private sector representatives from the health, education, social services, mental disabilities, substance abuse, and rehabilitation fields. Parents of children who have disabilities are represented as well as other interested Virginians.

Action for Prevention, Inc. provides educational opportunities to professionals as well as the lay public through annual conferences and other meetings, networking, and newsletters. Action for Prevention, Inc.'s major goal, however, is to identify critical areas in the prevention of developmental disabilities and develop strategies to address these areas.

Action for Prevention, Inc. was founded in 1983 following a statewide mental retardation/ developmental disabilities prevention conference. That conference produced an Action Agenda of over 100 recommendations and Action for Prevention, Inc. was established to ensure these recommendations were carried out. In 1989 a Developmental Disabilities Grant was awarded to the Virginia Institute for bringing the Action Agenda up to date by reviewing the status of the 1983 recommendations and adding others relevant to the prevention of developmental disabilities in Virginia. Developmental Disabilities Grants are administered by the Developmental Disabilities Office in the Department of Mental Health, Mental Retardation and Substance Abuse Services; funding priorities are determined by the Board for Rights of the Disabled, Virginia's "State Planning Council" for developmental disabilities.

A resource document developed by the Virginia Institute for Developmental Disabilities lists recommendations made by over 140 persons working in four task forces this past year (genetics, perinatal, early childhood, and school age/adolescence). Using this resource document, priority recommendations were selected and included in Invest in Virginia's Future: Prevent Developmental Disabilities. This document represents Action for Prevention's priorities for the 1990's. Every attempt has been made to make this document doable, manageable and of significance for a variety of audiences in promoting the prevention of mental retardation/developmental disabilities.

Action for Prevention's Action Agenda for the 1990's provides a brief introduction to the problem and then groups its priority recommendations into four broad areas: Education and Citizen Awareness, Access to Quality Care, Environmental Hazards and Injuries, and Research and Evaluation.

The total list of recommendations is included in the resource document The Virginia Agenda For Prevention of Developmental Disabilities in the 1990's. For copies of either document, please contact Action for Prevention, Inc. by mail at P.O. Box 2347, Richmond, VA 23218. This address can also be used for membership applications, committee contacts, and other information.

It is the hope of Action for Prevention, Inc. that your review of these documents will persuade you to join forces with us to prevent developmental disabilities.

The Board of Action for Prevention, Inc. gratefully acknowledges its debt to the Virginia Institute for Developmental Disabilities and to the more than 140 Virginians who contributed so much of their time and expertise to this project.

DEVELOPMENTAL DISABILITIES

"As we continue to work to prevent developmental disabilities, there is one important point which we must never lose sight of—we aim to prevent developmental disabilities, but that does not mean that we do not value disabled persons....Not only are we in need of more knowledge about the causes of developmental disabilities, but obviously we will need more money than is likely to be available. But now is not the time to point out what we cannot do, but what we can do."

(Source: Governor Charles S. Robb, 1983 Virginia Mental Retardation/Developmental Disabilities Prevention Conference)

Modern technology has advanced our ability to achieve optimal health for children beginning prior to conception. Despite these advances, many Virginians are born with developmental disabilities or acquire disabilities before they reach adulthood. An unacceptably large number of these disabilities is due to environmental hazards, preventable injuries, infections, poor nutrition, child abuse, and inadequate care during pregnancy - conditions which could be prevented or recognized early enough for effective remediation. Developmental disabilities should be prevented whenever possible for the benefit of the child and the child's family and for the economic benefits to society. The challenge for Virginia - and for all of us - is to do what should be done with knowledge of what can be done and with commitment that it will be done.

IN VIRGINIA

DEVELOPMENTAL DISABILITIES IN VIRGINIA: A PROFILE

- Seven percent of all births in Virginia (8,000 newborns) are low birth weight and 1000 of these are very low birth weight, with a high risk for developmental disabilities in those who survive the first months of life.
- Approximately 10% of Virginia's school age population are in special education programs.
- In 1987, in Virginians ages 5-19 years, there were 190 deaths and an estimated 19,000 non-fatal injuries due to motor vehicle accidents.
- In 1987, there were 260 babies born with fetal alcohol syndrome and 1 to 2 times as many born with fetal alcohol effects, conditions which cause developmental disabilities.
- Approximately 2% to 3% of newborns have a serious birth defect, many of which could have been prevented.

EDUCATION AND CITIZEN

[redacted]

"Most states doing one specimen screening for PKU and Hypothyroidism save $3.5 million per 100,000 infants screened" (Source: Office of Technology Assessment, U.S. Congress, December, 1988) Virginia screened nearly 83,000 infants in 1988. (Source: Virginia Department of Health)*

[redacted]

Professional education and public awareness often lag behind advances in technology and scientific knowledge which can be used to prevent disabilities. We must train Virginia's professionals and inform the public about the dangers of infections and substance abuse during pregnancy, the benefits of parenting education and early detection of children at risk for disability, and the availability of new tests for genetic disorders, new immunizations, and new programs to reduce perinatal risks.

- Alcohol use during pregnancy is the leading preventable cause of mental retardation.
- Screening for genetic disorders has been estimated to save $2 to $20 per dollar of cost in special services.
- According to 1987 report prepared for the Virginia General Assembly, health instruction at the elementary level in Virginia's public schools appears to be inadequate.
- In Virginia, we are 28,000 births a year to women who smoked during pregnancy. If pregnant women did not smoke, we could be a 20% reduction (100 births) in low birth weight babies, who are at risk for development problems.
- Hospital cost for each low birthweight baby range from $20,000 to $100,000, compared to an average cost of $4,000 for each normal weight, full-term baby.
- In 1988, 11,32 children were victims of abuse or neglect in Virginia. A comprehensive statewide prevention program will reduce and, hopefully one day, eliminate the incidences of child abuse or neglect.
- As of 1988, it is estimated that only 50% of pregnant women whose babies are at increased risk for chromosomal anomalies such as Down's Syndrome and neural tie defects have amniocentesis.

*PKU (Phenylketonuria) is an inherited metabolic disorder that causes mental retardation and developmental disabilities if not detected by newborn screening and treated in the newborn period.

AWARENESS

RECOMMENDATIONS

- Educate and encourage all perinatal health care providers to screen all pregnant women for high risk conditions which may affect pregnancy outcome including tobacco, alcohol, illicit drug use, and sexually transmitted diseases.
- Fund pre-conceptual education programs to promote a healthy preconceptual and pre-natal period for all women, including the avoidance of use of tobacco, alcohol, and other addictive substances, the prevention of infections, and the maintenance of optimal nutritional intake.
- Fund public awareness campaigns about fetal alcohol syndrome, the effects of tobacco, other drug use in pregnancy and risks for AIDS in women.
- Mandate and fund a maximum level genetic counseling program to address numerous needs in Virginia.
- Fund a full-time health educator at each state genetic center to educate a variety of audiences about genetic disorders. This funding must include educational materials.
- Improve the training of teachers/professionals in how to teach all aspects of Family Life Education.
- Fund a program for the education of health professionals and patients about the risk of birth defects resulting from such maternal conditions as diabetes, seizure disorders, nutritional deficiencies, and previous history of low birth weight infants.
- Train all providers serving families to recognize and deal with child abuse and/or neglect.

"Prevention and early intervention offer hope. It is the hope of changed lives. It is the hope of breaking cycles: cycles of undereducation and underachievement, cycles of domestic violence, cycles of poverty and cycles of emotional disorders. Prevention also offers the hope of saved resources including costs to the individual, costs to the supported institutions, and costs to businesses for lost productivity. (Source: Jeannie K. Bolles, "Investing in Virginia's Future", Conference proceedings of the First Lady's forum on Child Mental Health, May 13, 1997.)

[redacted]

Despite the availability of high risk obstetric care, advanced technology, perinatal centers, problem birth prevention programs, and high education programs such as smoking cessation, many pregnant women in Virginia lack access to these services. Economic, attitudinal, and transportation barriers especially affect pregnant women who are young, poor, single, and living in rural areas. All children at risk for disabilities do not have easy access to developmental and early intervention services or a guarantee of adequate health care, safety, education, and development.

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RECOMMENDATIONS

- Expand services for pregnant women and mandate third party payment for optimal prenatal care for all women following the Babycare Program model and increase funding for the Babycare Program.
- Mandate and fund prenatal testing for spina bifida and other neural tube defects, for example, maternal serum alpha-fetoprotein (MSAFP), and the follow-up of abnormal test results.
- Broaden existing policy to increase the use of nurse practitioners, certified nurse midwives, and physician assistants in prenatal and perinatal care.
- Fund a centralized state program to perform molecular genetics testing (including prenatal and carrier) for diseases such as Sickle Cell Anemia, Cystic Fibrosis, Duchenne Muscular Dystrophy, Huntington Disease, Fragile X Syndrome, and Neurofibromatosis.
- Increase funding for food programs for infants and young children, including the use of formula rebate programs. Maximize the use of WIC.

"Screening for fatal neural tube defects would cost $2 million to screen 100,000 women, but the total economic benefits would exceed $4 million." (Source: Center for Disease Control, Atlanta)

CARE

RECOMMENDATIONS

- Provide incentives to all perinatal health care providers to screen all pregnant women for high risk conditions which may effect pregnancy outcomes.
- Ensure state policy and funding to implement Public Law 99-457, Part H (Early Intervention Program for Handicapped Infants and Toddlers).
- Ensure that every child should have a primary health care provider for routine developmental, hearing, and visual screening.
- Encourage the Virginia Departments of Health and Education to establish and enforce minimum standards for school health services with adequate numbers of qualified nursing personnel.

ENVIRONMENTAL HAZARDS

"Spinal cord injury to children 0-18 years rose from 74 in 1986 to 99 in 1988 while head injuries to children 0-5 years rose from 2,396 in 1987 to 2,647 in 1988. (Source: Virginia's Combined Spinal Cord and Head Injury Registry).

"Only 37% of automobile occupants used seat belts in 1986; after the enactment of the Virginia Seat Belt Law, usage increased to 53% by March 1989." (Source: Virginia Division of Motor Vehicles).

THE PROBLEM

Congenital and acquired developmental disabilities often result from preventable, accidental, or intentional injuries, as well as preventable exposure to environmental hazards. Awareness of the hazards and increased screening for consequences of the hazards contribute to prevention. Unfortunately, many exposures are unexpected or impossible to avoid. For prevention to be successful, there must be a reduction in the hazards themselves, such as lead in the child's environment, maternal drug abuse, irresponsible driving, unsafe playground facilities, and conditions that may lead to child abuse by families and others.

- Between July 1, 1987 and June 30, 1988 in Virginia, for motor vehicles, 22% of accident victims used safety belts while 78% did not. The percentage of mortality with safety belts was 18%, without the belts the mortality was 82%.
- Lead poisoning has been identified as one of the most significant hazards facing children. The effects of lead poisoning on the cognitive and physical development of young children are not reversible.
- There have been 24 reported cases of AIDS in children younger than 13 in Virginia, most due to maternal infection from IV drug abuse.
- A pregnant woman is exposed on the average to 5 medications during pregnancy. This may have a major negative effect on the fetus.
- During the period of July 1, 1987 through June 30, 1988, there were 8,094 founded incidences of child abuse under the age of 18 and 3,248 suspected incidences.

AND INJURIES

RECOMMENDATIONS

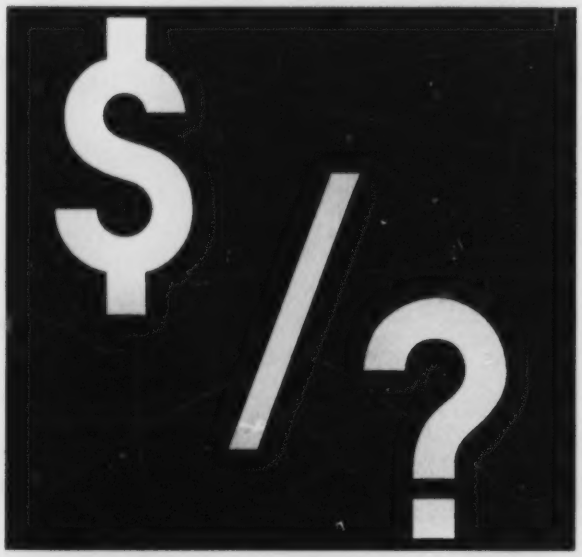
- Promote concept of "every child a wanted child" and improve access to family planning services to reduce risk of child abuse following unwanted pregnancy.
- Legislate the requirement for inspection and removal of lead before children can occupy buildings likely to contain lead.
- Identify children at risk for abuse and neglect and provide an array of support services to their families.
- Strengthen current seat belt legislation to cover any person in the vehicle and enforce this more vigorously.
- Encourage the Virginia Department of Health, Education, and Transportation to develop collaborative programs and, if needed, legislation aimed at the prevention of central nervous system injuries resulting from all terrain vehicles, skateboards, bicycles, mopeds, sports injuries, and playground injuries in the schools and community.
- Fund a statewide system for information on environmental hazards during pregnancy.

RESEARCH AND

"There is major research needed to develop markers that can be used clinically in newborn and developing infants to identify risk factors, pre- and post-natal...Specific areas needing research include early human gestation, effects from toxic exposure, effects of drugs on intrauterine and extrauterine growth, the spectrum of fetal alcohol effects and their associated risk factors...and the potential for in utero therapy. (Source: Report of the Study Group on Mental Retardation and Developmental Disabilities, U.S. Department of Health and Human Services, September 1986).

Information about Virginia children who have or who are at risk for preventable disabilities is incomplete and is not being collected and analyzed systematically. In the past, public pressure for increased direct services resulted in few funds for research and evaluation in the area of prevention. The high cost of these direct services makes it imperative to prevent disabilities whenever possible and to demonstrate the cost benefits of doing so.

Without prevention research, policy makers lack information necessary to allocate prevention resources that will yield the greatest savings in human and economic costs. Virginia needs systematic, comprehensive information to identify trends and to establish casual factors in order to plan programs to meet changing needs. Research and evaluation are urgently needed both to assess the effectiveness of new prevention programs and to establish a comprehensive data base to evaluate prevention efforts statewide.



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EVALUATION

RECOMMENDATIONS

- Compile and summarize empirical evidence regarding the predictions of child abuse and neglect and the degree of effectiveness of various intervention approaches.
- Initiate research to further define the relationship between unintentional injuries and developmental disabilities.
- Provide funds for long-term evaluation of Family Life Education programs across the state and use the data to improve the quality of programs around the state.
- Expand the study of programs directed toward prevention of risk taking behaviors in teens, such as substance abuse, and continue and expand those programs with proven validity.
- Study and publicize the incidence of Chlamydia and HIV infections in pregnant women as data become available in the next 2 years; study current reporting data for incidence of Gonorrhea and Syphilis in pregnancy.
- Fund VIRGINIA CARES (Congenital Anomalies Reporting and Education System) in the Department of Health and include money for evaluation of the program.
- Fund research into the combined maternal serum alphafeto protein (MSAFP) with human chorionic gonadotropin (hCG) and estriol with maternal age screening to detect Down's Syndrome and chromosal anomalies pregnancies.

Action for Prevention, Inc. expresses its appreciation to the following organizations. It is recognized, despite our best efforts, this list may not include all sources of information.

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CENTER FOR DISEASE CONTROL, ATLANTA

CHILDREN'S DEFENSE FUND

MEDICAL COLLEGE OF VIRGINIA/VIRGINIA COMMONWEALTH UNIVERSITY

OFFICE OF TECHNOLOGY ASSESSMENT, U.S. CONGRESS

UNIVERSITY OF VIRGINIA MEDICAL CENTER

VIRGINIA BOARD FOR RIGHTS OF THE DISABLED

VIRGINIA COMBINED SPINAL CORD AND HEAD INJURY REGISTRY

VIRGINIA DEPARTMENT FOR CHILDREN

VIRGINIA DEPARTMENT FOR THE DEAF AND HARD OF HEARING

VIRGINIA DEPARTMENT OF EDUCATION

VIRGINIA DEPARTMENT OF HEALTH

VIRGINIA DEPARTMENT OF MENTAL HEALTH,
MENTAL RETARDATION AND SUBSTANCE ABUSE SERVICES

VIRGINIA DEPARTMENT OF MOTOR VEHICLES

VIRGINIA DEPARTMENT OF SOCIAL SERVICES

VIRGINIA INSTITUTE FOR DEVELOPMENTAL DISABILITIES

VIRGINIA INTERAGENCY COORDINATING COUNCIL
FOR EARLY INTERVENTION (PL 99-457, PART H)

VIRGINIA PERINATAL ASSOCIATION

and

ACTION FOR PREVENTION, INC. 1983 AND 1985 CONFERENCE PROCEEDINGS

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